

# UCLA

## Presentations

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Beyond Privacy: The Emerging Ethics of Data Reuse

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## Beyond Privacy: The Emerging Ethics of Data Reuse



Trusted evidence.  
Informed decisions.  
Better health.

**WHO GETS ACCESS TO RESEARCH DATA?  
AND WHO GETS TO DECIDE?**

# Facebook Cambridge Analytica scandal: Sheryl Sandberg apologises for 'big mistakes'

Facebook

## How to check whether Facebook shared your data with Cambridge Analytica

People who fear their information may have been used by Cambridge Analytica can go to a new help page

Alex Hern

@alexhern

Tue 10 Apr 2018  
07.52 EDT

## Facebook to notify 4 million people about latest data leak

POSTED 8:05 PM, AUGUST 22, 2018, BY TRIBUNE MEDIA WIRE AND CNN WIRE

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The Evening Stan



# Cambridge Analytica and Online Manipulation

It's not just about data protection; it's about strategies designed to induce addictive behavior, and thus to manipulate

224901

Anguish: Mother finds hospital has baby's tissue samples

# I'm grieving again for my stillborn son

By Rebecca Hughes

A MOTHER discovered tissue samples from her stillborn baby are being held at a Gwent hospital more than eight years after his death.

Rhosalyn Hawkins, 36, of Heol Hamelin, Abergavenny, gave birth to Ethan at Nevill Hall Hospital, Abergavenny, on June 13, 1993. He weighed 6lb 12oz and was stillborn.

After initially refusing to allow a post-mortem examination she agreed, and it showed Ethan died of natural causes.

"Ethan was buried with my grandparents at Llanfoist cemetery," she said.

"I was watching a television programme about organ and tissue retention recently and it made me think. I always believed this sort of thing would not happen at Nevill Hall.

"But I decided to ask, and I rang the patient liaison officer at the Royal Gwent Hospital, Newport.

"Three weeks later I had a letter from Martin Turner, the chief executive of the Gwent Healthcare NHS Trust, confirming some very small tissue samples were taken at the post mortem for further examination, and these are still being held at Nevill Hall."

In his letter, Mr Turner also explained organs or tissue samples may be sent away for a second opinion, for teaching or as part of a research project, or to contribute to improved medical treatment.

But Ms Hawkins said she felt she was back to square one in the grieving process.

"I was devastated when I found out because I thought I had buried him whole.

"It's like burying another child. I just want other parents who may have been in the same position as me to know that this practice of retaining tissue is happening."

A leaflet by the Retained Organs Commission says retaining tissue is not illegal, but concerns following organ retention means the legal framework is being reviewed to clarify when material should be kept and for how long.

The leaflet adds: "Following a hospital post mortem, performed with the agreement of relatives, it



DEVASTATED: Rhosalyn Hawkins holds a picture of her stillborn son, Ethan James Jorge. Tissue samples from Ethan's body are being held at Nevill Hall Hospital, Abergavenny

is now accepted that their consent or otherwise to the retention of organs or blocks and slides should have been obtained at the time."

A spokesman for the Gwent Healthcare NHS Trust said: "The

feelings expressed by Ms Hawkins on such an emotional and personal matter are obvious and the trust has endeavoured to provide as much information and assistance as possible.

"But it is important to underline that the trust acted within policies and practices accepted throughout the country. New guidelines are now being considered."

• Editorial comment: page 12





# 'This is just the beginning': Using DNA and genealogy to crack years-old cold cases

Police are harnessing consumer DNA sites to solve old murders, which could spur a massive clearing of unsolved crimes.

by Kate Snow and Jon Schuppe / Jul.18.2018 / 4:30 AM ET

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**POLICY FORUM** | GENETICS AND PRIVACY



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## Genealogy databases and the future of criminal investigation

Natalie Ram<sup>1</sup>, Christi J. Guerrini<sup>2</sup>, Amy L. McGuire<sup>2</sup>

+ See all authors and affiliations

*Science* 08 Jun 2018:  
Vol. 360, Issue 6393, pp. 1078-1079  
DOI: 10.1126/science.aau1083

## Modeling 3D Facial Shape from DNA

Peter Claes<sup>1</sup>, Denise K. Liberton<sup>2</sup>, Katleen Daniels<sup>1</sup>, Kerri Matthes Rosana<sup>2</sup>, Ellen E. C. Laurel N. Pearson<sup>2</sup>, Brian McEvoy<sup>3</sup>, Marc Bauchet<sup>2</sup>, Arslan A. Zaidi<sup>2</sup>, Wei Yao<sup>2</sup>, Hua T. Gregory S. Barsh<sup>4,5</sup>, Devin M. Absher<sup>5</sup>, David A. Puts<sup>2</sup>, Jorge Rocha<sup>6,7</sup>, Sandra Belez Rinaldo W. Pereira<sup>9</sup>, Gareth Baynam<sup>10,11,12</sup>, Paul Suetens<sup>1</sup>, Dirk Vandermeulen<sup>1</sup>, Jennifer James S. Boster<sup>14</sup>, Mark D. Shriver<sup>2\*</sup>

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## SHORT COURSE HIGHLIGHT

### Genomic Data and Models for Political Science



2018 APSA Annual Meeting & Exhibition

### THE UNIVERSITY OF CHICAGO PRESS JOURNALS

[The Journal of Politics](#) / [Vol. 73, No. 1, Jan. 14, 2011](#) / A Genome-Wide Analysis...



JOURNAL ARTICLE

#### A Genome-Wide Analysis of Liberal and Conservative Political Attitudes

Peter K. Hatemi, Nathan A. Gillespie, Lindon J. Eaves, Brion S. Maher, Bradley T. Webb, Andrew C. Heath, Sarah E. Medland, David C. Smyth, Harry N. Beeby, Scott D. Gordon, Grant W. Montgomery, Ghu Zhu, Enda M. Byrne and Nicholas G. Martin

*The Journal of Politics*

Vol. 73, No. 1 (Jan. 14, 2011), pp. 271-285

Published by: [The University of Chicago Press](#) on behalf of the [Southern Political Science Association](#)

DOI: 10.1017/s0022381610001015

<https://www.jstor.org/stable/10.1017/s0022381610001015>

/s0022381610001015

Page Count: 15

## AI that can determine a person's sexuality from photos shows the dark side of the data age

Devin Coldewey @techcrunch / Sep 7, 2017 [Comment](#)

More data, More Open, More  
Troubles.



# From HYPOTHESIS-DRIVEN RESEARCH

- Vetted research questions;
- “Results data” shared with publications;
- “Raw data” shared within trusted colleagues;
- Use of traditional Informed Consent;

Scientists control access and reuse of the raw, individual-level data they collect.

# To HYPOTHESIS-FREE DATASETS

- Idea of research data as “fungible” goods;
- “Raw data” made available on open repositories, for reuse by the science community at large;

Scientists DO NOT control access and reuse of raw, individual-level data they collect.

Repurposing hypothesis-free open  
data: Regulating Access as a  
ITERATIVE PROCESS

# HOW TO CONTROL ACCESS TO OPEN HEALTH DATA?



# 1 – Do not control

- Benefits in exchange of unrestricted reuse of data
  - Shared economic benefits with the patients;
  - Or to provide access to treatments and health care.
- “Solidaristic” approaches
  - Participants are willing to risk some harm for the benefit of others.
- Do not control access, but tax secondary reuses of the data

## 2 – Distributed control

- **Keep the donors in the loop:** inform participants about research studies, including findings and discoveries, that use the donated data.
- **Provisionary reuse:** give donors the option to pull out their data from a repository if a misuse occurs.
- **Distributed responsibility:** Have an external and independent party to supervise the moderation process.



# Questions for Discussion

- Who gets to decide how and when to reuse open data?
  - Who should be responsible for decisions about access and reuse?
  - What is the role of the data donors in regulating access to data?
- When should research data be shared within closed collaborations, and when can these be made openly available?
- As data users, what kind of factors should we take into consideration when reusing open data?
- What are the technical challenges of moderating access and reuse of bio open data?



Christine Borgman



Bernie Boscoe



Peter Darch



Milena Golshan



Irene Pasquetto



Michael Scroggins



Cheryl Thompson



Morgan Wofford